

## **LAST THING ON THE TO-DO LIST**

A Service by Lois Hansen (with Fritz Hudson)

October 26, 2008

### **Opening Words**

Carefully  
the leaves of autumn  
sprinkle down the tinny  
sound of little dyings.

And skies sated  
of ruddy sunsets  
of roseate dawns  
  
roil ceaselessly in  
cobweb greys and turn  
to black for comfort.

Only lovers  
see the fall  
a signal end to endings  
  
a gruffish gesture alerting  
those who will not be alarmed  
that we begin to stop  
in order simply  
to begin  
again.

"Late October"- Maya Angelou

### **Sermon**

Ten years after his neurologist confirmed that Alan, my beloved husband of 59 years, had Parkinson's Disease, he chose to end his life. The plaque, characteristic of his illness, accumulated silently on his brain, interfering with control of his voluntary muscles, leaving stiffness, tremor and finally, immobility. He could no longer change positions in bed, get in or out of bed alone, dress himself, or move from lift chair to wheel chair without great difficulty. His hands held a fork or spoon, but guiding them for eating was challenging. More disturbing were the episodic bouts with hallucinations, brought on by various prescribed drugs. These diminished or stopped as their cause was identified. At best this took a few days but one series came and went for a couple of years ending only when a new doctor identified the culprit. Priceless gifts to him and to us who loved him appeared when those drugs were stopped: he enjoyed conversation, and could give remarkably good counsel when asked by his sons and daughter; he enjoyed food and mealtimes with his family. Most remarkably, his quick, topical wit still flashed insight and humor on events of the day.

Since Alan planned to die at home in his bed, a circumstance in which police always come to the home to learn the circumstances, we recorded a statement from him on video as he sat in our family room. No one outside our family has seen it because we were not questioned. When I watched it recently our cat, who slept against his leg in the bed we shared and moved with him when he needed a hospital bed, was attentive to his voice and image. Finally Kitty hopped on the TV stand and put his nose gently against Alan's face on the screen. Although we filmed the explanation for legal reasons, it has had important personal value—to him, because his voice which had weakened with illness, emerged stronger and decisive as he talked about his intention to take control for himself--and to me because hearing him brings him close. I want to share a part of this now with you:

DVD February 2007: Alan Hansen's recorded statement:

*I'm doing this recording to convey to you some of the ideas I have had about my life and about ending it and what's going on in my head with respect to that.*

*The first thing is that I'm a happy person because of the kinds of things I've been able to do and the kinds of interrelationships I've been able to enjoy. Those things are draining from me as I get to be weaker and as I get to be more uncomfortable with my life and my opportunities to do the things I like to do. So therefore I'm trying to capitalize on the good life I've had and not pollute it with an uncomfortable period of time when I did not feel good or when I was in pain or whatever negative things like that would be going on. I don't feel the need to show the world that I can endure X period of time of difficulty before I die.*

*The difficulty I'm anticipating is based in the times I've had with the developing Parkinson's disease that I've had for nine years. And although the Parkinson's has been mild for the most part, it's becoming more disabling as we go along. I find myself being more dependent on other people and arrangements and unable to contribute much to what's going on around me which I don't like. I like to be a contributor. In fact that's an important part of my life is to contribute to other people.*

*My plan for ending my life is a very real thing to me and I intend fully to carry it out as expressed. I intend to die having enjoyed my life and not suffering unnecessarily the erosions of old age. When the balance sheet goes negative it's not a time for heroics, particularly when it affects not only me but my whole family.*

*Therefore it is indeed my choice to end my life at my choosing which I intend to do as scheduled . . . period.*

We human beings are creative creatures. We choose a multitude of approaches to life and love and learning and change. Each of us also is faced with life circumstances over which we have no control. And we are influenced variously by the time and place we live, our common culture, our fears, and opportunities offered or not offered.

Today, most Americans, when asked about the end of their lives express hope for a “good death.” This is commonly explained to include being at home, in bed, surrounded by loved ones, free of pain, not violent. Yet a recent survey of 2713 Nebraskans about arrangements they had made for the end of life, drew a response from only 12 percent. Two-thirds of the 12 percent had not completed Living Wills. In 2001 a medical journal reported that in the United States 42% of deaths take place in hospitals, and 36% in nursing homes. The journal article began with this question: “Why, at the beginning of the twenty-first century, do we need a grassroots movement to help us learn something as basically human as how to die?” I will say more in a few minutes about this grassroots movement.

I speak today about our family experience because I believe that honest discussion about death and dying is deeply buried in the conversational closet .... so hidden that we can't think seriously about what we want, make decisions or plan. For the most part our cultural death rituals and terminology are stereotyped, surrounded by fear, mystery, and lack of information about choices available. I am particularly pleased to share our family experience here in the context of a series about love, because for our family Alan's final time in his mortal body was about love. It was about his choice to live according to his personal values, about the rest of us joining with and supporting his journey because we loved him.

The thinking Alan and I did about what we wanted from life and from the end of life, was deeply influenced from the time we were in our early 20's by our experience in six Unitarian-Universalist congregations. It began with making wills to provide for our children and much later making living wills and power of attorney for health care. In the 1960's, with other Omaha Unitarians we founded the Midland Memorial Society, which maintained a file for end of life instructions of its members and interviewed funeral directors to find the one or two who were then willing to offer simple, low-cost services when requested.

Over the years I attended several helpful end-of-life programs at UU General Assemblies and read whatever I could find. Perhaps 15 years ago I spoke with our physician about my own intent to die peacefully and with dignity when quality of life was gone for me. She said that under the law she could give palliative care and relieve pain but nothing more, and I understood that was true. She urged me, however, “Tell all of your children and especially be certain that those who live far away know your beliefs and what you want. Too often those nearby have seen and accepted a loved one's declining health, while those far away, not faced with daily realities, want every intervention possible to keep the person alive.” Her advice was helpful.

Nine or ten years ago when Alan learned he had both Parkinson's Disease and Macular Degeneration, we talked to our children one at a time and in a general way about both of our intentions to make our own health care decisions, possibly including when to end our lives. They asked some questions, and assured that no finality was close at hand, accepted what we had to say.

In Lincoln, sometime in the late '70's we involved ourselves with the national grassroots organization that has evolved to become “Compassion and Choices.” The national leadership in this group demonstrates courage and ethical and moral stature that are an inspiration to me. In

2004 the speaker at our small Nebraska meeting, was Dr. Peter Goodwin, a national board member of Compassion and Choices. He was a family physician and faculty member at the University of Oregon Medical School. He had been a leader in support of the Oregon Death with Dignity law which today allows a physician who follows its specified protections for patient and doctor, to prescribe for a terminally ill person, a drug which the individual can self administer to bring about a peaceful and painless death. His activism was spurred by a cancer patient in the 1980's, who begged Dr. Goodwin to help him die. At the time the doctor refused, worried about his own vulnerability and being negatively judged by medical colleagues. The patient suffered a terrible death; Dr. Goodwin felt guilty and responsible about what he viewed as his own cowardice. He joined the board of what was then The Hemlock Society, determined that physicians needed to do better for terminally ill patients and influenced the transformation to Compassion and Choices. Today, although Oregon has had 10 years of successful experience of the Death with Dignity law, no other state has passed a similar law.

Compassion and Choices' multi-faceted counseling and advocacy program honors its commitment that: "Everyone deserves a death that honors their life." It offers information about end of life choices, professional consultation and emotional support to patients who are terminally ill and their families. It does not provide or administer the means for aid in dying. Its advocacy was instrumental in passage last month of a California law which now requires physicians to give patients who request it, information including all legal end-of-life options. Without such information and the subsequent counseling and support from a wonderful woman named Helen, our family story would be sadly different.

In August 2006 Alan was hospitalized with pneumonia for a few days, struggled for a month in a nursing home rehabilitation program, and returned home declaring he would never again go to a nursing facility or hospital. During the next couple of months his limitations increased: newspaper headlines were the only reading his macular degeneration allowed; chronic weariness closed in. After falling several times, he moved only in his electric wheel chair and had no interest in leaving the house even to sit on the porch. By November 2006 life had lost its savor for him. Nothing in our power to do held hope that the future could be better. He told me he was ready to end his life.

Making this wish into a plan took time. It now seems clear to me that anyone with a terminal disease who wants control of their own, needs information, a plan, necessary legal documents and to talk to their nearest and dearest well ahead of any need. Alan telephoned each of our four children in November, this time to tell them of his decision; they all came home immediately. They showed loving concern, some reluctance, a desire to make things better, and had a long telephone conference with a support counselor from Compassion and Choices. This warm and knowledgeable woman listened to all of us, questioned us, answered our questions, and advised us on procedures which required several months. Our children returned to their homes, and Alan and I began working through the To Do List. Our doctor, at Alan's request, referred him to a Hospice program. No one but the two of us was involved in any way with planning or obtaining the medication which he would administer to himself. We did nothing that was illegal. Fritz

Hudson and a physician friend in California were the only persons outside our family who knew our plans.

We shared important and beautiful time in those three months between telling our children his decision and the day he chose to be his last---February 23, 2007. All four came again in late February for time with one another and with Alan and me. I would not characterize our process as easy; we did a lot that was hard; but Alan was stronger in voice and spirit, and seemed relieved of anxiety. We owe much to our UU friends who offered welcome support during his illness.

Alan chose roast pork and baked potatoes when we gathered for a last dinner together---six at the table, sitting as we were when our children were growing up. We were by turns sad, thoughtful, appreciative, apprehensive, grieving, sharing, reminiscing, laughing. We cancelled the evening nurse's aide, and his three sons put him to bed. Next morning we each had time alone with him, then, lying in his sunny room on the hospital bed, his family around him, he took his pills and lost consciousness within five minutes. We stayed with him, talking, stroking his head, holding his hands. His strong heart beat through the afternoon and through the night. On Saturday, the 24th our Lincoln grandchildren and their mother joined us. The twins, then nine, came and went through the day. When he needed a break he went next door to his home for a while. When she needed time away she turned about a hundred cartwheels in our living room. The older girls stayed with their grandpa and the rest of us. The Hospice nurse came several times and was helpful. Near dusk, large, soft snowflakes covered the yard outside the glass door with an inch of snow. That evening, thirty-seven hours after he lost consciousness our beloved drew his final breath.

We all sat, then, in a circle on the floor beside him, around the plate with three candles---a blue, a white and a mulberry---that our daughter lighted as we began our vigil. Each of us in turn spoke a memory of Alan. It was a sacred time, full of love and loss, and it was a good death, following a long, good life.

I never doubted that love, our personal religious values and respect for human life guided our way. The love and support given by our sons and daughter, and the knowledge and support of the good people of Compassion and Choices were vital to our sense of rightness and peace through these days. I am grateful to them and to all of our UU friends.

Blessed be.

### **Closing Words**

Slowly receding surf,  
tide going down.  
A time ago  
you taught my eyes to see.  
  
And you are here  
alive  
within my memory.

No sliding world takes you.

You're here  
as sure as sea  
as sun.

I trust this slippery world  
because of you.

We're time and tide  
and life and love  
and linked  
with moving stars.

Raymond Baughan